

Facilitator Version

START

Strategies for Relatives



Facilitator Key

Numbers in blue boxes let you know how long each section should take.

Information in yellow boxes give instructions on how to facilitate tasks, as well as prompts for feedback and discussion.

Quotations in orange boxes should be said as written.

General Tips for facilitating the intervention

Before you start:

- **BE PREPARED:** Be prepared for each session, bring all materials and equipment and when appropriate integrate individual data in advance of the session.
- **STICK TO TIME,** try and follow time guidelines for each section. Give yourself a few minutes to get organized and engage the carer before you start.
- **TALK WITH THE CARER** about how they can make protected time for them to do the session, preferably without the person they are caring for present.

You will need:

- Manuals
- Pens
- Watch
- Relaxation CDs
- CHOICE leaflets

General tips:

- If you feel that the examples are not relevant to the carer, try to think with the carer and between sessions of more relevant examples. **If a section really does not apply to them, for example their relative does not have behaviours that they find difficult or they have already planned for the future, spend less time on these sections.**
- Carers will understand and use ideas from the manual at a different pace and will vary in their literacy levels. It is important to adapt the pace to match the person you are delivering to and to help if necessary with notes so that is not a burden. Repeat ideas if that is necessary.
- Encourage carers to write down key ideas and plans.
- Be observant; notice which sections work well and how the carer responds. Keep notes on what worked well and any challenges you faced.
- Undoubtedly problems will arise in sessions that haven't been anticipated. These should be recorded after the session to discuss during supervision.
- Balance making carers feel listened to and understood, whilst keeping focused on the manual. During talking points – facilitate discussion whilst being aware of sticking to time.

Key themes:

- Carers have a great deal of experience particularly of a family member, it is important to value their experience and build upon their existing strategies and knowledge throughout the sessions.
- The importance of trying out tasks between sessions is highlighted in the first session. Try to reinforce the benefits of doing tasks throughout and offer encouragement when between session tasks have been completed.
- The purpose of the intervention is to support carers to make changes to their and their relative's behaviour and lifestyle and to find their own solutions. Therefore it is important to ask questions that encourage and guide them to develop their own strategies based on the manual content instead of telling them what to do.

Introduce yourself and ask: “Some people find it helpful to think of themselves as a carer, others describe themselves as just acting the way a relative does. What would you like for me to call you and refer to you as?”
Remember what term/name they prefer and use it throughout the sessions.

10 mins

Introduction

“Draw diagrams or write in it and you can look back over the manual in between sessions and after the sessions are finished”.

- This is your manual to use.
- These sessions are about you, and how to maintain or improve your well-being when caring is stressful. It is designed to be adaptive to individual needs.
- Caring is challenging, and many skills are needed. The sessions will focus on your thoughts, feelings, and reactions to looking after someone with dementia. We will look at:
 - Strategies to manage behaviours which often accompany dementia, so they are less upsetting. They are based on **what has been shown to work**.
 - Strategies focusing on your sense of well-being, including ways to relax.
- You may think **‘I have tried it all before’** and you are probably already using some of the strategies. We hope to build on what you do know and introduce new ideas, doing more of what works and less of what does not.
- Not everything in here may feel useful to you, but most people find a lot of parts to be helpful. So we would encourage you to do the whole course.

“Everything you say is confidential, as it is in all health settings”.

“I may come from a different background to you and we will have different experiences, but I have experience of working with people from a range of backgrounds”.

Key Point:

Although not all difficulties will change, putting what you learn in START into practice should make things better now and in the future.

“I now feel I have all the tools before she gets worse.”

“Sometimes I sit and go through my manual and there is a peace and understanding that someone is there with me.”

What to expect

Throughout the sessions we will be focusing on:

- Providing skills to cope with behaviours related to your relative's dementia.
- Developing skills to help you, including changing unhelpful thoughts, communication, assertiveness, relaxation, and pleasant activities.
- Planning for you and your relative's future needs.
- Helping you maintain the skills you have learned over time.

There will be eight sessions each lasting **one hour and each will include:**

- A new topic to discuss.
- Making a plan for you to try out between sessions.
- A new way of reducing stress.
- **Strategies to put into practice** during, and between sessions.

“After completing each session there will be an exercise for you to do at home, before the next session. Although it may be difficult to find time, people benefit from completing these and are able to gain more from the session. It will allow you to become more aware of the ways you or your relatives behave and help you put new skills into practice”.

START

- Session 1:** Stress and well-being
- Session 2:** Reasons for changes in behaviour
- Session 3:** Making a behaviour plan
- Session 4:** Behaviour strategies and unhelpful thoughts
- Session 5:** Communication
- Session 6:** Planning for the future
- Session 7:** Pleasant events and your mood
- Session 8:** What works? Using skills and strategies in the future

“Each of the 8 sessions are outlined below for you to refer back to.”

START

Session 1: *Stress and well-being*



Plan for today

“This is the contents page for you to refer back to”

Refer to the contents but do not read the full list

Introduction to the course p. 3

Overview of dementia p. 7

Behaviour and emotions p. 9

Managing the stress that caring brings p. 12

Social support p.14

Managing stress: The signal breath p. 15

Summary p. 17

Putting it into practice p. 18

For each session:

- Encourage the carer to write down **what works** or key strategies or plans to refer back to.
- If content is clearly irrelevant or does not fit, **miss it out.**
- When setting exercises at the end, check that they remember what is in the plan if not explicitly covered in the content.

- Dementia is a **physical illness** of the brain
- Dementia is not a normal part of ageing. It is an illness which can affect several areas of a person's life, including:
 - Memory
 - Concentration
 - Thinking
 - Judgement
 - Behaviour
 - Visual processing
- Dementia is associated with more than 50 different disorders. The most common cause is Alzheimer's disease, followed by Vascular Dementia and then Lewy Body Dementia.



“DEMENTIA” is an umbrella term

Alzheimer's disease
Vascular dementia
Dementia with Lewy bodies
Parkinson's disease dementia
Fronto-temporal dementia

- Dementia affects the lives of many different people, including the person with dementia and his or her family members. It can lead family members to feel overwhelmed or guilty, even when they are doing everything they can to help.
- Everybody's dementia is different as the brain is affected in different ways and people are unique. Nearly everybody has difficulty in remembering and learning new things.
- Dementia is progressive and problems change over time. Even if you do not feel stressed now, this manual can help prepare you for the future.



“I don't think people realise the impact caring has on the person providing the care. They don't realise that caring for someone with Dementia involves 24 hour care. It's not something you can just put a bandage on and that's it, your job is done”.

Key Point:

Learning skills to manage symptoms of dementia can allow family carers to feel more in control of their life circumstances.

“List the specific symptoms or behaviours that you have noticed, start with what you find most concerning or difficult”

If they struggle to think of behaviours you can prompt:

- Losing interest in family / hobbies
- Asking the same questions over and over
- Saying insensitive/ uncharacteristic things
- Talking more / less / differently



Talking point:

Can you tell me the problems and symptoms you have noticed?

1. _____
2. _____
3. _____
4. _____
5. _____

- A behaviour is something specific and observable that someone does. Some behavioural changes that can occur with dementia include:
 - Asking the same question repeatedly
 - Thinking things have been stolen, when they have forgotten where they have put things
 - Doing embarrassing things in public
 - Sleep difficulties

Key Point:

These behaviours are frustrating and difficult to change but it is important to remember they are not intentional.



- Behaviours are often related to feelings and may not mean what you think.
- Sometimes people cannot express what they feel in words, so their behaviour can be a clue to what they are feeling.

Talking point:

Let's use the table below to consider behaviours that you or your relative may do when you are feeling a particular way.

Prompts may be:

Sad – crying, not eating, staying in bed

Pain – groaning, making a face

Angry – Hitting, pacing, clenching face

Feeling or emotion	Related behavior
Sad 	1. Talks less 2.
Pain 	1. Doesn't want to be touched 2.
Angry 	1. Shouts 2.

Now let's look at the behaviours on page 9:

- Which of these most concern you?
- Which one causes you the most stress?
- If there are no behaviours that concern you, is there anything else about the situation with your relative that causes you stress?

Prompt may be:

Lack of interest

Recording Behaviour

Noticing when a particular behaviour happens and how it makes you feel can help you to notice patterns and find new ways to manage and respond.

“Here is a way to record behaviours. During the next week, please use this to write down the things your relative does (or you do when caring for your relative) that you would like to change. Try and be specific”

Day	Morning/Afternoon /Night	Who was there?	Trigger	Behaviour	Reaction	What strategy did you try?	What happened?

10mins

Managing the stress that caring brings

“We are now going to move on to talk about recognising and managing the stress that caring can bring, which many carers experience.”

- Stress is physical and emotional strain.
- Caring for people with dementia can be physically and emotionally draining.
- Over time, stress can impact on your health and well-being and affect your sleep. While the challenges cannot be avoided, you can take steps to reduce the effect on you.

Common stress reactions include feeling:



“You’ve talked about some of these emotions.”

“Are there any other emotions that you experience?”

“Other stress reactions include:

- Physically tensing your muscles
- Feeling sweaty or sick
- Your heart beating fast”

Key Point:

We will provide you with some new skills and techniques which do not take up too much time and are easy to do at home, even when your relative is around.

Social support

- Talking things over can relieve stress by giving people a chance to discuss their thoughts and feelings but caring for someone can make it hard to keep up with friends and relations.
- Caring can be particularly difficult if the person you are looking after is reluctant to accept help from anyone else.
- Over these sessions we will be discussing local sources of support where you can meet others who have similar experiences.
- And how to let friends and family members know when you need help, or maybe just a break.



“We know from talking to carers that even asking for help from family can be complicated, but we will be coming back to this in later sessions at various points”

Talking point:

What social support do you have and find helpful? Is there anything else you think might help?

Key Point:

Caring for someone with dementia does not have to be a lonely experience. It is okay to let friends and family know when you need help, or maybe just a break.

“During the sessions we are going to help you to learn both how to recognise stress and gain control over it, we are not here to say, “When you are stressed, just relax”, but to give you tools to reduce the effect on you. Some of the techniques will work for you and others won’t, the key is to find the ones that fit for you. We are now going to try one of these techniques called the ‘Signal breath...”

10mins

Managing Stress 1: *The Signal Breath*

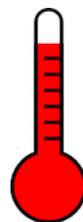


- The Signal Breath is a simple stress reduction technique that may help when you are coping with stressful situations.
- You can use it *anywhere*, at *any time*, and it is *quick*.
- Your relative may enjoy trying these exercises as well.

“First, please rate your level of stress or tension right now, before we practice the signal breath”.

Stress Rating Before Exercise

First, please rate your stress or tension right now before we practice **the Signal Breath**.



- 5 = Terribly tense**
- 4 = Really tense**
- 3 = Moderately tense**
- 2 = Slightly tense**
- 1 = Not at all tense**

Q! On a scale of 1 to 5, how would you rate your tension? _____

“Now let’s practice together. Sit comfortably in your chair and follow my lead...” Read out the instructions below and then repeat.

Signal breath: Practice session



1. Take a deep breath



2. Tighten your shoulders and arms, hold it for a few seconds



3. Now, let it go and say *calm* To yourself

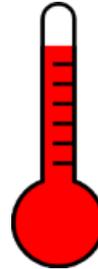


4. Allow your jaw, shoulders, and arms to go loose and limp

“Please practise at least once a day in different situations. When you practise the signal breath, it is best to do it only two or three times at once. More than that may make you feel lightheaded”

Tension rating after exercise

How would you rate your tension level now after **the Signal Breath?**



- 5 = Terribly tense**
- 4 = Really tense**
- 3 = Moderately tense**
- 2 = Slightly tense**
- 1 = Not at all tense**

Q! Now, please rate your tension or stress level from 1 to 5 _____

Discuss:

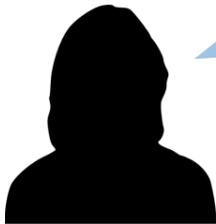
- Did your level of tension change?
- What was this experience like for you?
- Can you think of specific times when this might have helped?

Summary

Today, we have talked about:

- Dementia
- Behaviour and emotions
- Managing the stress that caring brings
- Social support
- Managing stress: The signal breath

“Thinking about what we have discussed, is there any information from today’s session that you would want to share with someone else (e.g. a family member, a friend or a neighbour)”.



“Relaxation exercises helped before bedtime to clear the mind”

10mins

FOR NEXT WEEK: *Putting it into practice*



- **The signal breath:**

“Here is a CD of the managing stress exercises we will be trying over the next weeks. If you would prefer to listen to the relaxation exercises on your smart phone or tablet, you can download the files”

Try to practice this every day and to use it in stressful situations. See if it helps.

You can listen to these managing stress exercises any time on your CDs or by visiting: <https://soundcloud.com/user-971142120/sets/start-relaxation-tracks>



- **Behaviour record:**

“Look back over the session to help you with this, there is an extra copy of the form on the next page...”

Talk through the behaviour record form and check that they have understood the task.

Please use the record on page 20 to write down the things your relative does that concern or upset you. Please, try to use it every day.

START *Putting it into Practice*

- Is there anything that might get in the way?
- Is there anything that might make it easier?

Behaviour Record

Day	Morning/Afternoon /Night	Who was there?	Trigger	Behaviour	Reaction	What strategy did you try?	What happened?

